Review Article

Supporting communication for patients with neurodegenerative disease

Melanie Fried-Oken*, Aimee Mooney and Betts Peters
Institute on Development & Disability, Oregon Health & Science University, Portland, OR, USA

Abstract.
BACKGROUND: Communication supports, referred to as augmentative and alternative communication (AAC), are an integral part of medical speech-language pathology practice, yet many providers remain unfamiliar with assessment and intervention principles. For patients with complex communication impairments secondary to neurodegenerative disease, AAC services differ depending on whether their condition primarily affects speech and motor skills (ALS), language (primary progressive aphasia) or cognition (Alzheimer's disease). This review discusses symptom management for these three conditions, identifying behavioral strategies, low- and high-tech solutions for implementation during the natural course of disease. These AAC principles apply to all neurodegenerative diseases in which common symptoms appear.
OBJECTIVES: To present AAC interventions for patients with neurodegenerative diseases affecting speech, motor, language and cognitive domains. Three themes emerge: (1) timing of intervention: early referral, regular re-evaluations and continual treatment are essential; (2) communication partners must be included from the onset to establish AAC acceptance and use; and (3) strategies will change over time and use multiple modalities to capitalize on patients' strengths.
CONCLUSIONS: AAC should be standard practice for adults with neurodegenerative disease. Patients can maintain effective, functional communication with AAC supports. Individualized communication systems can be implemented ensuring patients remain active participants in daily activities.

Keywords: Augmentative and alternative communication, communication disorders, dementia, progressive aphasia, ALS

1. Introduction

One of the most difficult challenges for individuals with neurodegenerative disease is the insidious onset of communication impairments (Houston, 2000). While initial symptoms may not interfere with speech intelligibility or language functions, at some point in disease progression, many people become unable to rely on natural speech or writing to meet their daily communication needs (Beukelman, Garrett, & Yorkston, 2007). Speech-language pathologists (SLPs) and assistive technology providers have developed communication supports that compensate for these

deficits and ensure that patients retain the ability to communicate throughout their lives (Beukelman, Fager, Ball, & Dietz, 2007). In this article, a range of communication supports, referred to as augmentative and alternative communication (AAC) strategies, techniques, and devices, are described (Beukelman & Mirenda, 2013). The American Speech-Language-Hearing Association defines AAC as all forms of communication that are used to express thoughts, needs, wants and ideas (American Speech-Language-Hearing Association, n.d.). Data are presented demonstrating that AAC provides communication options for individuals with a wide range of neurodegenerative diseases that affect motor speech, language, and/or cognitive function. This review focuses on amyotrophic lateral sclerosis (ALS), primary progressive aphasia (PPA), and Alzheimer's disease (AD), but these AAC

*Address for correspondence: Melanie Fried-Oken, Ph.D., Oregon Health & Science University, CDRC, P. O. Box 574, Portland, OR 97239, USA. Tel. : +1 503 494 7587; Fax: +1 503 494 6868; E-mail: Friedm@ohsu.edu.

evaluation and treatment principles apply to common symptoms associated with many other neurodegenerative diseases, including Parkinson's disease and Parkinson's Plus syndromes, dystonia, Huntington's disease, muscular dystrophy, multiple sclerosis, frontotemporal dementia, and other types of dementia.

2. Communication support

Communication support is defined broadly as "anything that improves access to or participation in communication, events, or activities. Support includes strategies, materials, or resources that are used by people with impairments or by others who communicate with people with impairments. It involves modifications in the environment around the person with impairments or modifications to activities in which people engage. It also includes supportive attitudes that foster communication participation. Finally, support includes policies and practices of agencies and institutions that foster communication success" (page 9) (King, Simmons-Mackie, & Beukelman, 2013). According to Simmons-Mackie (2013), there are key assumptions that justify intervention with communication supports. While these foundational concepts are described within a chronic aphasia context, they resonate for patients with neurodegenerative disease as well: (1) The ultimate goal of all treatment is to enhance participation in communicative life. Regardless of the stage of the neurodegenerative process, the patient and his communication partners can set goals that achieve meaningful outcomes. (2) Communication is a collaborative enterprise. Since meaning is negotiated between and among participants, those with communication challenges and their partners must develop strategies and resources to send and receive messages successfully. (3) Communication support is an ethical issue. It is the responsibility of the interventionist to identify and establish any method, strategy or resource that might help a patient communicate more successfully.

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities presents a Communication Bill of Rights (Table 1) that clearly states that all people with disabilities, including those with severe speech and language impairment secondary to neurodegenerative disease, have a basic right to affect, through communication, the conditions of their existence (National Joint Committee for the Communication Needs of Persons with Severe Disabilities, 1992).

The World Health Organization's *International Classification of Functioning, Disability and Health (ICF)* (World Health Organization, 2001) provides a useful framework for AAC intervention, which is delivered at the participation level rather than the impairment level of disability (Worrall & Frattali, 2000). The *ICF* defines participation as "involvement in a life situation" (page 123), and places activities and participation, environmental barriers and facilitators, personal factors, as well as body function and structure within a model of health conditions. Borrowing from an aphasia framework again (Kagan et al., 2008), the A-FROM (Aphasia: Framework for Outcome Measurement) presents a heuristic that has been adapted from the ICF to increase relevance to communication disorders in a clinically friendly format.

Table 1
NJC communication bill of rights

Each person has the right to:

- request desired objects, actions, events and people
- refuse undesired objects, actions, or events
- express personal preferences and feelings
- be offered choices and alternatives
- reject offered choices
- request and receive another person's attention and interaction
- ask for and receive information about changes in routine and environment
- receive intervention to improve communication skills
- receive a response to any communication, whether or not the responder can fulfill the request
- have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
- have AAC and other AT devices that function properly at all times
- be in environments that promote one's communication as a full partner with other people, including peers
- be spoken to with respect and courtesy
- be spoken to directly and not be spoken for or talked about in the third person while present
- have clear, meaningful and culturally and linguistically appropriate communications

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communication needs of persons with severe disabilities. ASHA, 34(Suppl. 7), 2–3.

Within the participation framework, the focus of communication intervention shifts from an impairment- or restoration-based approach to one that emphasizes compensation for lost function, with reliance on AAC (Fried-Oken, Rowland, & Gibbons, 2010). For example, instead of improving speech intelligibility through drill and practice exercises, AAC would compensate for a speech impairment with tools, environmental and partner adaptations, and behavioral changes. Rather than working on goals to return patients to their previous levels of functioning, AAC provides ways to remain engaged in daily activities with alternative compensatory approaches or durable medical equipment. An on-screen keyboard and joystick, for instance, might be provided for a person with limited upper extremity skills for typing, permitting computer use with alternative writing access methods. AAC encompasses a variety of strategies, techniques, and devices, ranging from simple yes/no eye blinks to sophisticated computer-based systems and speech-generating devices. For patients with neurodegenerative disease who present at different stages of communication impairment, these supports initially will facilitate and maintain participation in daily activities. A mechanism must be in place to re-evaluate and adjust communication supports over time as needs and skills change. Acceptance of multiple communication options by the patient and his/her family, as well as the early inclusion of communication partners in all aspects of treatment, are critical elements that are likely to ensure AAC acceptance and successful outcomes.

2.1. No-tech AAC

No-tech or unaided AAC refers to any natural form of communication that uses the human body, with no other equipment required (Vanderheiden & Yoder, 1986). Examples include vocalizations, tongue clicks, eye movements and blinks, and gestures. One technique often used by patients with intact upper extremity function is writing letters in the air (Fried-Oken, Howard, & Stewart, 1991). Another approach called partner-assisted scanning involves a communication partner reciting aloud the letters of the alphabet or a list of messages, waiting for a signal (e.g. eye blink, eye movement or vocalization) to indicate the desired option (Bauby, 1998). While formal sign languages such as American Sign Language may also be considered no-tech AAC, they are not often used with people with degenerative conditions due to the time and effort required for both the individual and communication partners to learn a new language. To aid caregivers in the consistent interpretation of communicative movements, facial expressions, and sounds, a gesture dictionary may be constructed that describes an individual's gestures and pairs them with their associated meanings (i.e. throat clearing means 'I need ice chips').

2.2. Low-tech AAC

Low-tech AAC involves the use of non-computer based equipment, from pen and paper to alphabet boards (Wu & Voda, 1985), communication books and simple alerting systems. Individuals experiencing challenges with speech intelligibility can write messages or draw pictures to communicate intent (Lasker, Hux, Garrett, Moncrief, & Eischeid, 1997). Similarly, communication partners can support language expression by using a written choice strategy. During conversation, if a person is unable to respond verbally, the partner writes down possible responses. The person with the communication impairment then can indicate his choice by pointing to the selected word (Lasker et al., 1997). Alternatively, communication partners can enhance comprehension by supplementing spoken language with gestures, written words or phrases, drawings, or diagrams. This technique, termed augmented input, occurs dynamically during conversation, providing an effective low-tech communication support (Ball & Lasker, 2013; Wallace, Dietz, Hux, & Weissling, 2012). Communication books and boards may be developed that are text-based (with letters, words, or whole sentences), symbol-based (with photos or drawings representing topics and messages), or a combination of the two, and should be customized to each individual's personal needs and interests (Khayum, Wieneke, Rogalski, Robinson, & O'Hara, 2012). Communication boards and books are commonly used with direct selection, where the patient indicates the desired items with an anatomical pointer or device (e.g. hand, finger, head or chin stick, stylus, or laser pointer). Some communication boards are designed for use with eye movements (e.g. ETRAN) (Goosens' & Crain, 1987), or as visual supports for the partner-assisted scanning method described above. Appropriate size, format, selection method, text, and symbols must be considered to personalize the low-tech options based on assessment results.

When natural speech is still a viable option, writing and alphabet boards can augment intelligibility. Traditionally referred to as supplementation strategies, this definition is currently expanding beyond alphabet, topic

and gestural supplementation to include augmenting speech with pictures via mobile technology and conversation management strategies (Hanson, Beukelman, & Yorkston, 2013). Individuals with severe dysarthria benefit from pointing to written topic cues or letters on an alphabet board to clarify speech productions (Hustad, Jones, & Dailey, 2003). A technique called alphabet supplementation or first-letter pointing uses an alphabet board to improve speech intelligibility and has been found to increase intelligibility by 5 to 69%, with greater improvements for those with more severe dysarthria (Hanson, Yorkston, & Beukelman, 2004; Hanson, Beukelman, Heidemann, & Shutts-Johnson, 2010). The speaker points to the first letter of each word on the alphabet board as he says it, which slows down speech, creates pauses between words, and provides additional cues to the listener.

2.3. High-tech AAC: Speech-generating devices

A speech-generating device (SGD) is an electronic AAC system that allows the user to type or select a message that is spoken aloud. When considering an SGD for a patient with motor speech, language or cognitive impairments, at least four features must be examined: (1) the technology that will house the SGD; (2) the symbols to represent language on the machine (either letters for spelling, photos or pictures, or a combination of symbols); (3) the access method or means to select language on the device; and (4) the output method or type of speech that will be generated (Fishman, 1987).

SGDs are either 'dedicated' and function solely for AAC, or they are 'integrated', with access to AAC and to other computer applications and functions. Most SGDs presently are built on general technology platforms, either on a laptop or on a touchscreen tablet that is placed into a custom-built box. Communication apps are very popular and exist to turn a standard tablet computer or smartphone into an SGD. A list of apps for AAC can be found at www.janefarrall.com. The size, portability, durability, capacity, and flexibility of the SGD must be considered as individuals with neurodegenerative diagnoses change their physical and communication needs over the natural course of the disease.

Speech output may be either digitized (recordings of natural speech) or synthesized (a computer-generated voice that uses text-to-speech software to convert a typed message into speech) (Fishman, 1987). Digitized messages can be recorded by the user while intelligibility is still adequate, or by another speaker with

a similar-sounding voice or the same gender. Messages that are produced with digitized speech must be determined in advance. Synthesized speech offers the advantage of allowing the user to produce novel messages, although current synthesized voices lack natural inflection, intonation, and the ability to express emotion. Individuals who know in advance that they may lose their speech can record phrases in their own voices for eventual use on an SGD. This process is known as message banking (Costello & Dimery, 2014; Costello, 2014; Santiago & Costello, 2013). A similar process called voice banking is used to create customized synthetic speech based on the user's own voice. One reliable voice banking system, named Model Talker, has been implemented in a number of current software programs for text-to-speech applications (Bunnell, Lilley, Pennington, Moyers, & Polikoff, 2010; Yarrington, Pennington, Gray, & Bunnell, 2005; Yarrington et al., 2008).

The term 'access method' refers to the way the user produces messages on an SGD. SGDs can be adapted for access by individuals with a variety of physical abilities, including those who are unable to type on a keyboard or touch screen. Movements of the hands, feet, head, or even the eyes can be used to control a computer cursor (Fager, Beukelman, Fried-Oken, Jakobs, & Baker, 2012), and switches can harness even the smallest muscle movements to make selections as the computer scans through available options (Fishman, 1987). Brain-computer interface systems will one day allow individuals with little or no voluntary muscle activity, such as those with total locked-in syndrome, to control an SGD using only their brain activity (Fager et al., 2012). Dedicated SGDs produced by AAC manufacturers, along with accessories for access and mounting, are covered by Medicare, Medicaid, and most private insurance providers. An evaluation by an SLP and a physician's prescription are required.

2.4. Communication partners

Conversation partner inclusion is a key component of all AAC interventions (American Speech-Language-Hearing Association, 2005). Since communication is not a solitary activity, the behavior and attitudes of communication partners influence the success of AAC use (Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007; Smith & Connolly, 2008). Interacting with a person who has a language, cognitive, or speech impairment places a novel set of demands on the communication

partner, especially if the partners have been lifelong conversants before symptoms developed (Chapey et al., 2001). One of the standards of care in optimizing communication for people who are losing natural speech is finding a way to improve the communication effectiveness of various partners (Ball & Lasker, 2013; Ball, Fager, & Fried-Oken, 2012). Effective partners understand turn taking and engage in balanced conversations, ask questions but also share in topic shifts, and co-construct messages with a range of communication supports (Thiessen & Beukelman, 2013). One way to determine the role of each communication partner is to place them within a social network. The Social Networks Inventory (Blackstone & Hunt-Berg, 2003) was developed for this purpose within the AAC field, and provides a framework for delineating personal goals for each patient-partner dyad.

Communication partner training is a well-established, evidence-based intervention for chronic aphasia (Lyon et al., 1997; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010), and has been emphasized for AAC. Training refers to formal instruction as well as opportunities to practice communication supports in a variety of environments with those who need AAC (Thiessen & Beukelman, 2013). Partner training must focus on enhancing interactions by determining the optimal qualities of partner behaviors that support verbal engagement, permitting an individual to maintain independence and participate in daily activities (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Kent-Walsh & McNaughton, 2005; Simmons-Mackie et al., 2010). Binger and colleagues (2012) delineate effective roles for AAC stakeholders, and create a model for instruction and preparation of communication partners. Critical issues that must be addressed include managing partner attitudes towards AAC technology, the establishment of priorities for social engagement, and the preservation of the AAC user's roles.

Conversation partner training must continue to evolve throughout the course of the disease, shifting to match the patient's changing needs and abilities. As impairments worsen, partners take on increased responsibility to assist with communication (Kagan, 1998; Kagan et al., 2001). The timing of intervention and the introduction of new communication supports are two fundamental principles that remain critical when integrating partners into communication management.

3. Communication supports for patients with progressive speech and motor impairments

3.1. Symptomology

Approximately 80 to 96% of people with ALS will become unable to meet their communication needs through natural speech at some point during the disease progression (Beukelman, Ball, & Pattee, 2004; Sitver & Kraat, 1982). Like other aspects of ALS, communication difficulties vary significantly from person to person (Hanson, Yorkston, & Britton, 2011). A person with ALS may present with a mixed flaccid-spastic dysarthria that is characterized by impaired articulation, slowed speech, reduced vocal loudness, rough or breathy voice quality, hypernasality, fatigue or shortness of breath with speech, reduced utterance length due to impaired breath support, or a combination of any of the above (Ball, Beukelman, & Bardach, 2007; Darley, Aronson, & Brown, 1969; Kühnlein et al., 2008). While these symptoms are always progressive, the rate of change varies. ALS is often associated with cognitive changes, ranging from mild impairment to frontotemporal dementia (Goldstein & Abrahams, 2013; Lomen-Hoerth et al., 2003; Neary, Snowden, & Mann, 2000), or with language impairments including semantic dementia or PPA (Ball et al., 2007; Taylor et al., 2013).

Individuals with advanced ALS who elect to undergo tracheotomy and receive mechanical ventilation may progress to a locked-in state (Hayashi, Kato, & Kawada, 1991; Hayashi & Oppenheimer, 2003). Individuals with classic locked-in syndrome (LIS) have lost all voluntary muscle function aside from blinking and limited eye movement (Bauer, Gerstenbrand, & Rumpl, 1979; Murguialday et al., 2011). In total LIS, even eye and eyelid movements are lost (Bauer et al., 1979; Murguialday et al., 2011), along with any possibility for communication through movement-based signals. Novel techniques are being developed to address the communication needs of individuals with classic and total LIS, as medical interventions evolve for this clinical group (Beaudoin & De Serres, 2008; Casanova, Lazzari, Lotta, & Mazzucchi, 2003; Doble, Haig, Anderson, & Katz, 2003; Schjolberg & Sunnerhagen, 2012).

3.2. Intervention

The case study (see Fig. 1) illustrates the wide range of technologies and communication strategies that one person with ALS may require over the course of

Julia is a 67-year-old woman with a busy social life, a tight-knit family including several grandchildren, and a passion for volunteer work. She was diagnosed with limb-onset ALS eight years ago. Shortly after her diagnosis, she began attending a multidisciplinary ALS clinic, where an SLP provided education about the communication changes associated with ALS, introduced the concept of AAC, and recommended message banking. Julia had experienced little change in her speech or voice at that point, and recorded several messages for future use on a speech-generating device.

One year later, Julia reported that she had difficulty making herself heard over background noise and experienced fatigue with speech. Julia's articulation was still intact, but vocal loudness was reduced and her voice was rough and breathy. At that time, a voice amplifier was recommended. Julia attached the amplifier to the arm of her power wheelchair, and used it frequently when speaking in noisy environments or for long periods of time.

Two years later, Julia presented with mild-to-moderate dysarthria. She was referred for an AAC evaluation to identify appropriate options for supporting her communication. By this time, upper extremity strength and range of motion were severely impaired, and she was unable to access either high- or low-tech AAC with her hands. She demonstrated excellent strength, endurance, and range of motion in her lower extremities. After trialing several SGDs, Julia selected a dedicated SGD with multiple alternative access options. She controlled the SGD with her feet and legs, using a large trackball resting on the right footplate of her wheelchair and a switch mounted near her left knee. The SGD was mounted to her wheelchair, where she spent most of her time. The messages that she had banked soon after her diagnosis were now programmed into phrase pages within the SGD software. When the SGD was unavailable, Julia relied on both no-tech and low-tech AAC. She used her residual speech for words and short phrases to familiar partners, and communicated with head movements, eye gaze, facial expressions, and by pointing with her feet or tracing letters onto her wheelchair footplate with her toe.

Several months after receiving her SGD, Julia learned that her respiratory function had deteriorated to dangerous levels. After extensive discussion with her family and healthcare team, she underwent a tracheotomy and began receiving mechanical ventilation. She continued to use her system of communication supports during and after her recovery, but eventually experienced a decline in function in her lower extremities. When Julia began to report fatigue and reduced accuracy using the foot-operated trackball to control her SGD, her SLP initiated a trial of eye gaze access and later ordered an eye gaze attachment for the SGD. She and her caregivers were trained in partner-assisted scanning as a low-tech communication option. Julia continues to use her AAC system to communicate with family and friends, direct her everyday care, interact with her healthcare team, host dinner parties, cheer at her grandsons' soccer games, and participate in other daily activities.

Fig. 1. Communication supports for a woman with ALS.

disease progression (see also Doyle & Phillips, 2001). Many individuals with ALS begin with strategies to augment their natural speech in the early stages of the disease, but increase their use of alternative methods of communication, including high-tech SGDs, as speech intelligibility continues to decline. Traditional articula-tion and voice therapy has been found to be ineffective in improving intelligibility in people with dysarthria secondary to ALS; in fact, strengthening exercises for the oropharyngeal musculature result in worsening of dysarthria (Dworkin & Hartman, 1979; Watts & Vanryckeghem, 2001). Changes in access method (e.g.

switching from a touch screen to a joystick to eye gaze access) are common due to ongoing motor function deterioration (Beukelman, Fager, & Nordness, 2011). It is important for people with ALS to have multiple options for communication in different situations, with different partners, and under different conditions (e.g. in noisy environments or when the user is fatigued) (Roman, 2014). Since the presentation and progression of speech, motor, and cognitive changes vary significantly among different people with ALS (Ringel et al., 1993), a customized system of communication supports should be designed for each individual.

Timely assessment and intervention is essential for successful AAC implementation. Yorkston, Beukelman, Strand, and Bell (1999) have delineated a speech staging system for ALS that can be used to track symptom progression and set treatment goals. The five stages begin with "no detectable speech disorder", when intervention will focus on education and planning for future change, and progress to the point of "no useful natural speech", when AAC replaces natural speech. Clinical pathways based on the five stages provide more specific guidance on appropriate assessment, intervention, and education for each stage (RERC on Communication Enhancement, 2004a; RERC on Communication Enhancement, 2004b). Speaking rate should be monitored in the early stages, since it is a reliable predictor of an imminent decline in speech intelligibility. When speaking rate drops below 125 words per minute or intelligibility falls below 90%, an AAC referral is recommended (Ball, Willis, Beukelman, & Pattee, 2001). Throughout the process of speech deterioration, AAC treatment must be tailored to the individual's current needs and abilities while simultaneously preparing for future challenges.

Because ALS affects motor function and often cognitive function as well as speech, patients should be regularly screened for changes that might affect communication. Deterioration of physical abilities or cognitive status may render communication supports unusable (Beukelman et al., 2011; Roman & Woolley Levine, 2006). In these cases, the patient should be re-evaluated to determine a new access method, new AAC strategies, or modifications to existing strategies. Changes in multiple areas of functioning can be particularly challenging; for example, a man with ALS may require eye tracking to access his SGD due to declining motor function, but may have difficulty learning this new skill because of cognitive impairment (Roman & Woolley Levine, 2006). Some individuals with cognitive impairment may reject AAC intervention

(Ball, Beukelman, & Pattee, 2004). Early identification of cognitive changes and early instruction in multiple forms of AAC, including simple, low-tech strategies, can help avoid such difficulties. Screening tools such as the ALS Cognitive Behavioral Screen (Woolley et al., 2010) can monitor cognitive functioning, preparing the patient and partners for changes in AAC techniques and access. Individuals with co-occurring cognitive impairments or dementia offer challenges to the interventionist. Often the balance of interactions shifts for these patients, so that their communication partners provide additional language supports in a compassionate manner.

Individuals who opt for mechanical ventilation and progress to a locked-in state also challenge current AAC practices. Brain-computer interface (BCI) technology is a new communication access method for people with severe speech and physical impairments (Fager et al., 2012; Soderholm, Meinander, & Alaranta, 2001), and may eventually allow AAC use by people with total LIS. BCI systems provide a means of controlling a computer using only brain waves, with no neuromuscular activity required (Wolpaw, Birbaumer, McFarland, Pfurtscheller, & Vaughan, 2002). In a BCI, brain signals are acquired either invasively (via implanted electrodes) or noninvasively (via electroencephalography [EEG] or other methods), and changes in brain activity are used as control signals to make a selection or control a directional cursor on a computer screen. Several BCI systems are in development for use in communication by people with LIS (Blankertz et al., 2006; Fabiani, Gratton, Karis, & Donchin, 1987; Farwell & Donchin, 1988; Krusienski, Sellers, McFarland, Vaughan, & Wolpaw, 2008; Ryan et al., 2011; Schalk, McFarland, Hinterberger, Birbaumer, & Wolpaw, 2004; Treder, Schmidt, & Blankertz, 2011). Researchers at the Wadsworth Center have placed their BCI 24/7 system in the homes of users with disabilities for trials of independent use (Sellers, Vaughan, & Wolpaw, 2010; Winden et al., 2012). The RSVP Keyboard™ BCI features a simplified interface designed to be well-suited for individuals with visual and/or cognitive impairments, and is also being trialed in the homes of potential users (Oken et al., 2014; Orhan et al., 2012). Unfortunately, current BCI-based communication systems are still unreliable, cumbersome, and do not work for some potential users (Akcakaya et al., 2014). This technology needs improvement and is not yet widely available for independent home use, but shows promise as a future AAC access method for individuals with the most severe physical disabilities, including those with advanced ALS.

Regardless of the methods and strategies used, AAC is widely used and valued by people with ALS and their communication partners. In one study, individuals with ALS report use of high-tech AAC for an average of 28.4 months, including use through the last month of life (Ball et al., 2007). Ninety-four percent of participants in the same study relied on low-tech or no-tech strategies, as well, with increased reliance on no-tech strategies toward the end of life. A number of interaction goals have been met by these communication supports, including meeting basic needs, providing and requesting information, and participating in social interchanges (Fried-Oken et al., 2006); remaining employed (McNaughton, Light, & Groszyk, 2001); and connecting with others through email, telephone communication, social media, and other electronic means (Fried-Oken et al., 2006; Shane, Blackstone, Vanderheiden, Williams, & DeRuyter, 2012).

4. Communication supports for patients with progressive language impairment

4.1. Symptomology

Primary progressive aphasia (PPA) is first identified by the insidious onset of a gradual loss of word finding, object naming, or word-comprehension skills. Language deficits are the primary presenting symptoms, with cognitive function relatively spared in first two years. The syndrome was first described in 1982 by Mesulam, who later developed a set of diagnostic criteria (Mesulam, 1982; Mesulam & Weintraub, 1992; Mesulam, 2001). Further refinement in classification resulted in description of three variants characterized by distinguishable clinical presentations: progressive nonfluent aphasia (PNFA), semantic dementia (SD) and logopenic/phonological progressive aphasia (LPA) (Gorno-Tempini et al., 2011). The publication of consensus criteria for PPA is supported by many efforts to further delineate distinct linguistic, semantic and phonological characteristics for each variant (Carthery-Goulart, Knibb, Patterson, & Hodges, 2012; Hoffman, Meteyard, & Patterson, 2014; Leyton & Hodges, 2014; Ogar, Dronkers, Brambati, Miller, & Gorno-Tempini, 2007; Thompson & Mack, 2014). Neuropathology has been identified as either fronto-temporal lobar degeneration or Alzheimer pathology with discrete patterns of regional cortical atrophy found to be lateralized in the left hemisphere (Mesulam et al., 2009; Mesulam, 2013).

No medical treatments are available to halt or slow the degenerative process, and there is limited pharmacological intervention for cognitive-behavioral symptom management. Ultimately, patients and families are left with an ambiguous forecast regarding communication changes and ways to cope as the disease progresses, wreaking havoc on ability to converse, connect interpersonally, and fully participate in daily life.

4.2. Intervention

Treatment for adults with PPA has been reported for the past 15 years (Beeson et al., 2011; Cress & King, 1999; Henry, Beeson, & Rapcsak, 2008; Rising, 2014; Rogers, King, & Alarcon, 2000; Rogers & Alarcon, 1998). Croot et al. (2009) provide a thorough review of therapies aimed at a variety of language impairments in PPA. Historically there have been two forms of intervention reported for patients with progressive language loss: impairment-directed intervention and activity/participation-based treatment. Carthery-Goulart et al. (2013) recently conducted a review of nonpharmacological interventions for PPA, and recommended impairment-directed therapies aimed at naming and lexical retrieval in semantic PPA as treatment options. Fueling further optimism, Jokel, Graham, Rochon, and Leonard (2014) discuss an encouraging trend for evidence in the behavioral treatments of anomia for people with PPA, with improvements noted in immediate treatment effects and in maintenance effect.

Participation-level interventions focus on development and utilization of compensatory strategies for the established goal of maximizing communication rather than trying to recover lost language (Khayum et al., 2012; Pattee, Von Berg, & Ghezzi, 2006). Similar to the proposed communication supports in this review, the focus of intervention shifts to compensatory strategies, such as communication boards and books or low-tech AAC devices in anticipation of further decline (Kortte & Rogalski, 2013).

Regardless of intervention type, treatment is based on two foundational principles: (1) treatment must be provided over the course of disease progression (Croot et al., 2009; Fried-Oken, Beukelman, & Hux, 2012; Jokel et al., 2014; Rogers et al., 2000) and (2) communication partners are key components of intervention at every stage (Beukelman et al., 2007; Pattee et al., 2006; Rogers & Alarcon, 1998). Staging communication supports for individuals with PPA is critical in order to maintain communication participation through the

James is a 61-year-old male retired from a 40-year career as a sales and marketing consultant. He enjoys walking with his wife, caring for twin grandchildren, and attending weekend religious services. He was diagnosed with primary progressive aphasia two years ago. Prior to his diagnosis, both James and his wife began noticing his forgetfulness of people's names, advancing to word-finding lapses during conversation. Working in the promotions business proved especially challenging, with particular limitations when talking on the telephone. James retired early secondary to his language difficulties. Although he noted minor changes in cognition, James was completely independent in all aspects of daily life, including driving, management of family finances and planning vacations.

James was evaluated by an SLP who discussed potential communication and cognitive changes associated with PPA. She introduced the concept of AAC and explained that the goal was to maximize communication for optimal participation at each stage of the disease. At this stage, impairment-based treatment was implemented to improve naming skills with semantic feature and phonetic cuing. James' wife was included in all appointments for both education and support. Recognizing that PPA is a progressive disorder, she recommended that speech and language therapy visits be periodic throughout the years.

Two years later, approximately four years into his diagnosis, James reported increased trouble recalling words, filling conversations with "ums, ahs and you knows". He noted difficulties with staying organized and keeping track of things in his home office. His wife conveyed that she assumed the task of preparing family taxes as James began to have difficulty with numbers. The SLP re-assessed cognitive function and noted changes in both attention and executive function. Treatment, at this stage, included the introduction of visual AAC tools and partner training for communication breakdowns and repair. A number of AAC supports were trained to mastery, including use of a personalized communication book in conversation and an iPad for maintaining a calendar, setting alerts to prompt task initiation, and developing a visual lexicon of photographs to compensate for language loss. James's wife learned how to rephrase and simplify questions, provide choices, and give verbal and environmental cues for communication. James learned to use a single-message device to call 911 and give his name and address in the event of an emergency, allowing him to be home alone for a few hours.

As his communication impairments progressed, James stopped initiating conversation and remained silent unless spoken to. A group of communication partners, including James's adult children, long-time neighbors, and church friends, were taught how to provide language support to James with a variety of partner-assisted communication strategies and techniques. Highlighting co-construction, the SLP demonstrated ways to lead successful interactions and enable James's participation in family events using multi-modal techniques (including remnants, calendars, photo books, financial statements, and community bulletins). She introduced the concepts of environmental cues like signage and word cards. Due to early intervention, development of an arsenal of AAC systems and comprehensive partner training, James has been able to maximize communication and participation throughout the course of his disease.

Fig. 2. Communication supports for a man with primary progressive aphasia.

progressive disease (King, Alarcon, & Rogers, 2007). Fried-Oken (2008) proposes a framework to guide intervention and training for both people with PPA and their communication partners, based on the stages of disease progression (presented in Fig. 2, above). In the early stage, intervention is based on the need to convey specific information in specific situations. In this stage, strategies for pacing and word retrieval,

and identification of topic and key words are recommended. As generative language declines, it becomes necessary to put patients' internal lexica in front of them. Mid-stage treatment recommendations include reliance on printed materials, idiosyncratic gestures, communication boards or cards, SGDs (often tablet computers with apps), and partner/family training to provide multi-modal input to support comprehension for the person with PPA. Late stage treatment includes prompting, errorless training for pointing to referents and teaching the partners to provide basic choices for expression. Treatment focuses both on meeting an individual's current communication needs and on preparing for future changes, with an emphasis on compensating for language deficits rather than trying to reverse them (Fried-Oken et al., 2012). The roles that communication partners play in the lives of people with PPA are essential. As an individual loses skills, the partner assumes more responsibility for communicative interaction and message co-construction (Fried-Oken, 2008).

5. Communication supports for patients with progressive cognitive impairment

5.1. Symptomology

Progressive loss of cognitive skills is a frequent symptom of many neurodegenerative diseases, and the common characteristic of dementia syndromes (Rowland, 2005). Communication supports are a critical intervention strategy for patients and their partners at different stages of cognitive loss, and often are used to facilitate conversation, maintain independence as long as possible, and assist with caregiving and behavior management (Bourgeois & Hickey, 2007). In the cases of dementia in Parkinson's disease, Parkinson's Plus syndromes (such as progressive supranuclear palsy and corticobasal degeneration), Huntington's disease, AIDS encephalopathy, multiple sclerosis, or ALS, significant motor impairments and sensory loss must be considered during treatment planning. For patients who present with cortical dementias, including Alzheimer's disease (AD), Pick's disease, frontotemporal dementia (FTD), and dementia with Lewy bodies, impairments in attention and communication are common (Bourgeois & Hickey, 2009). This review will focus primarily on Alzheimer's disease and probable AD (McKhann et al., 1984).

The communication and cognitive deficits associated with AD can be divided according to early, mid, and late stages (Bayles, Kaszniak, & Tomoeda, 1987; Bayles, Tomoeda, Cruz, & Mahendra, 2000; Bourgeois & Hickey, 2009; Kempler, 1995; Kertesz, 1994). In the early stage, many communication skills remain intact, including speech sound production, grammar, and conversational abilities. Oral reading, writing, and reading comprehension are preserved. There is good sustained attention and concentration, and the patient is aware of language and memory lapses. Deficits are noted in word finding, comprehending complex conversation and abstract language, and explicit memory retrieval. By the middle stage, increasing deficits are noted in word finding, understanding of complex instructions and tasks, reading comprehension, and many domains of memory. Relative strengths include speech sound production, grammar, oral reading, and implicit or procedural memory. The late stage of AD is characterized by severely limited expressive language, inappropriate word choices, limited vocal productions (sometimes to the point of mutism), severely limited auditory comprehension, and severe memory deficits across all domains. Affective responses to sensory stimuli and music remain strong, and the patient often cooperates with appropriate tactile, visual, and affective cues. If treatment is expected to increase appropriate communication behaviors during the natural course of this disease, then it must occur early, include communication partners as early as possible, and rely on multiple modalities to capitalize on the patient's strengths.

5.2. Intervention

Communication treatment for people with AD has three main purposes: (1) to maintain independent functioning as long as possible; (2) to maintain quality of life through supported participation and engagement in selected activities; and (3) to maintain activities that are personally relevant and within functional contexts (Bourgeois & Hickey, 2009). The focus of most interventions must be compensatory, that is, the use of stimuli or strategies that compensate for cognitive impairments so that the individual can function in an adaptive manner during meaningful, satisfying activities (Fried-Oken, Rau, & Oken, 2000) (see Fig. 3).

Within the past two decades, communication treatment has evolved to address participation-based goals, rather than trying to improve cognitive-communication impairments that progressively worsen. As such, intervention should either rely on (1) over-learned processes (procedural memory) or preserved abilities for effortless acquisition of new information, or (2) errorless

Dennis is a 72 year old retired banker who presented in an AAC clinic with a diagnosis of moderate Alzheimer's disease. He currently lives in an assisted living facility with his wife, May. Dennis complains of word finding problems, losing track of time, people, and goals, and memory loss. He avoids making telephone calls because he can't follow the conversation. He is not using a computer anymore to follow the stock market or send emails to his children, and he has difficulty reading. May adds that her husband no longer helps with chores at home, and she has taken over the household finances. He is not remembering his daily schedule, and is having trouble with his personal hygiene routine. He attends church weekly, but does not start conversation with old friends, and often cannot remember their names. May stated that she or a friend or family member must accompany Dennis when he goes out.

A number of visual supports and low-tech approaches were integrated into Dennis and May's daily communication. A large-print daily schedule was set up in the kitchen, with photographs depicting activities for the day. Each photo was placed on a symbol line with Velcro in order of the activities. When an activity was completed, the photo was taken off the symbol line and placed in a 'finished' bin. A hygiene symbol line was placed in the bathroom, with photos of each activity that needed to be completed in the morning and evening. As in the daily schedule, the photos could be removed from the symbol line as each task was completed. To maintain church participation, Dennis' friends agreed to be photographed and their pictures were placed in a small photo book that he could carry with him. Since Dennis could read phrase-level personally relevant text, the book contained a set of questions and personal statements (such as, "How is your wife?" and "I'd like to get together soon.") that he could share during refreshments after church. May practiced reciting the questions and personal statements with him weekly and reviewed the photos of friends every Sunday before attending church. Dennis started keeping a remnant box that contained small items from his activities. For example, he kept the ticket stub from a recent movie outing so he could show it to his son and didn't have to remember the name of the film or the theater, or the date of the trip. He kept a receipt from a dinner engagement with his sons so he didn't have to recall the name of the restaurant or what he ate when he was talking with May.

As Dennis' cognitive-communication skills decreased further, May was taught how to write down key words while she spoke short sentences so that Dennis had a visual cue to help process auditory-verbal information that was presented to him. She learned how to rephrase questions to help him understand what she was asking. She carried a small notebook and pen and wrote down visual-verbal cues about their schedule as they were out in the community or planning on leaving their home. For example, she wrote down GOING TO WATCH GRANT'S SOCCER GAME, and DINNER AT CHURCH, to help Dennis remember the activities. May started taking photos of these outings with her smart phone and placing them in a small memory book with short phrases. Eventually, Dennis moved to a memory care unit attached to the assisted living residence. He took his memory books and remnant box with him so he could reminisce with May during her daily visits.

Fig. 3. Communication supports for a man with Alzheimer's disease.

learning technique (Baddeley, 1992; Wilson, Baddeley, Evans, & Shiel, 1994) where structured, successful, frequent repetitive practice of new information enters memory. The former technique uses memory aids as communication supports (Bourgeois, Fried-Oken, & Rowland, 2010), and the latter technique uses spaced retrieval methods (Brush & Camp, 1998; McKitrick, Camp, & Black, 1992). An evidence-based systematic review of interventions for individuals with dementia (Hopper et al., 2013) found that the most commonly used cognitive-communication interventions techniques relied on errorless learning, spaced retrieval, or verbal instruction/cueing. A comparison of training strategies that used both spaced retrieval and external memory aids found evidence for both techniques (Bourgeois et al., 2003).

Bourgeois discusses internal and external memory strategies (Bourgeois, 1991). An *internal* strategy involves a process whereby a person must perform some mental manipulation of information to be remembered using mnemonic techniques, rehearsal or visual association strategies. Spaced retrieval falls into this category. *External* memory strategies include devices, equipment or visual cues for recognition of information and automatic processing. AAC supports are considered external strategies.

External memory aids include memory books, wallets, and cards, memo boards or planners with photos, biographical statements, and stories, as well as simple technology. Bourgeois (1990, 1992) clearly demonstrated that memory wallets improve the quality of conversation, increase production of factual, unambiguous statements, and encourage greater participation in conversation for people with AD. In the early stages of dementia, common technology such as cell phones, voice message devices, talking photo frames, or watches can be used as memory supports. A smart phone, for instance, can function as an external memory support: the phone's directory can dial familiar numbers when a name or photo appears on the screen, the calendar can keep track of appointments, and the phone can be programmed to signal when medications need to be taken (Bourgeois et al., 2010). Even in the advanced stages of dementia, when communication deficits are severe and verbal output is limited, individuals with dementia rely on procedural memory to look at memory books, or listen while a communication partner reads and discusses the book. Memory aids, even remote schedule prompters, can also help to reduce problem behaviors such as repetitive verbalizations (Kuwahara, Yasuda, Tetsutani, & Morimoto,

2010; Yasuda, Kuwabara, Kuwahara, Abe, & Tetsutani, 2009). In response to repeated questions or requests, a caregiver can instruct the person with dementia to find the answer written on an index card or a page from a communication book, thereby reducing further repetitions (Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997). Talking Mats, a low-tech AAC system involving picture symbols and a visual rating scale, assists people with dementia in expressing their opinions and participating in decision-making (Murphy, Gray, van Achterberg, Wyke, & Cox, 2010; Murphy & Oliver, 2013). Fried-Oken and colleagues (2012) demonstrated that people with moderate AD could improve verbal conversation about personal, contextually relevant topics with communication boards as long as individuals were trained sufficiently how to use the communication supports. Simply placing a communication board in front of a person with AD without instruction produced no benefit. Voice output was found to distract people with AD and reduce their performance in conversation.

As with patients with PPA, conversation partners assume an ever increasing share of the responsibility for communication as the disease progresses. Small, Gutman, Makela, and Hillhouse (2003) examined the communication strategies used by caregivers with individuals with AD, and found that the following strategies significantly reduced communication breakdowns: asking one question or giving one instruction at a time; using short, simple sentences; and eliminating environmental distractions. Dijkstra, Bourgeois, Allen, and Burgio (2004) demonstrated that a communication partner may lower the demands of working memory during conversation by repeating questions posed to the patient, paraphrasing information, opening a communication book with personal information, or presenting verbal cues when the patient fails to engage in conversation. While these facilitators violate conversational rules when healthy partners are talking, they clearly support continuation of verbal interaction between patients with AD and conversational partners. Communication skills training programs for family members and caregivers are effective in improving communication with and attitudes towards people with dementia, reducing aggressive behaviors and agitation, and increasing quality of life (Eggenberger, Heimerl, & Bennett, 2013). Partner training significantly improves patient communication when strategies are embedded into daily care activities for care staff within residential and nursing homes (Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). Like patients with PPA, individuals with dementia may benefit from multimodal

input (e.g. writing key words, displaying remnants or objects) during early and middle stages of the disease to support receptive communication (Ho, Weiss, Garrett, & Lloyd, 2005; Lasker et al., 1997).

6. Conclusion

The insidious deterioration of motor speech, language, and cognition secondary to neurodegenerative disease significantly impacts patients, their communication partners, and medical management. Treatment must be aimed at helping persons with progressive communication impairments maintain independence as long as possible and retain basic societal roles for family, community, employment, and recreational pursuits for meaningful quality of life (Fox & Sohlberg, 2000).

Common treatment themes emerge, regardless of whether motor speech, language, or cognitive skills are affected. First, AAC timing based on the natural course of the disease is critical. Treatment must start early to ensure adequate time for AAC education, device acquisition, and training. Early referral to a speech-language pathologist is recommended. Consistent communication re-evaluations are necessary and must become standardized in management plans to document changes and adjust treatment, equipment, and goals with the patient and his/her significant others. Second, intervention must include communication partners from the start. Patients and their family members will only accept AAC supports as viable communication options if they learn to integrate them together into daily conversation. Partners, whether paid caregivers or family members, are the greatest advocates and are an essential component of successful communication supports. Finally, communication strategies must rely on multiple modalities to capitalize on the patient's strengths. Communication supports, including high-tech, low-tech, and no-tech approaches, should be tailored to the specific needs and abilities of each person, and should be modified throughout disease progression. A number of issues surface often when communication supports are proposed, and are discussed as important topics for future consideration.

6.1. Service provision

In order to provide the most appropriate communication services to patients with neurodegenerative disease, a well-trained healthcare team and knowledgeable 'finders' are imperative (Beukelman et al., 2011;

Zangari & Wasson, 1997). Finders include primary care physicians, neurologists, and therapists, who are often the first medical providers to evaluate a person with a degenerative disease. Once diagnosed, patients should be referred for speech-language pathology services. The nature of the speech-language pathology service varies, depending on setting, expertise, and composition of the clinical team. Funding for evaluation, treatment, and speech-generating devices must be in place. Currently, in the United States, SGDs are considered durable medical equipment and are available through private medical insurance as well as government-sponsored programs (Assistive Technology Law Center, 2012). Advocacy organizations, such as the ALS Association and the Muscular Dystrophy Association, are available to guide patients and families through the policy and practice barriers that exist in health care systems. Chat rooms have sprung up on the Internet, such as http://www.alsforums.com and www.alzheimersonline.org, where individuals with progressive diseases and their caregivers discuss their experiences and raise questions about medical management and family issues. Patient registries and research nets exist where the latest medical and technological treatments are discussed (e.g. www.ppaconnection.org). Tools for outcomes measurement that take into account patient centered outcomes and measure goals, such as maintaining independence in the home with adequate communication, must be available (Kagan et al., 2008; Patient Provider Communication, 2014).

6.2. Patient provider communication

One critical aspect of service provision is the establishment of effective relationships, values, and means of interaction between patients and their providers. This is especially important for the patients who are losing natural speech and language abilities secondary to their diagnoses, or those with low health care literacy skills who cannot understand everything that is happening to them (Weiss, 2007; Williams, Davis, Parker, & Weiss, 2002). In 2010, the Joint Commission published a roadmap for hospitals, entitled *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care*, that iterates suggestions for providers to interact with patients who are communication vulnerable (The Joint Commission, 2010). Adherence to intervention and patient satisfaction, both measures that affect patient outcomes, has been linked to effective patient-provider communication

(Haskard Zolnierek & DiMatteo, 2009). In other words, the way that information is presented to the patient and the relationships and values established with the patient will affect their overall communication management. Yorkston, Baylor, Burns, Morris, and McNalley (2015) discuss how a provider's basic verbal interaction skills need to be supplemented with information about strategies for patients with communication disorders, including individuals who use AAC approaches. In order to participate in decision-making, for instance, messages in low-tech and high-tech devices must include words that allow for communication about the patient's diagnosis, treatment options, values, and end-of-life preferences so that the he or she has the ability to control health care decisions, to ask questions, and to respond to inquiries from providers.

The provider is a communication partner who is responsible for elements of shared decision making during the natural course of the disease. Health care providers are included in one of the partner circles of the Social Network Inventory (Blackstone & Hunt-Berg, 2003) discussed earlier. Yorkston and colleagues (2015) delineate 11 roles that providers must consider: establish the patient's preference for the amount and format of presented information; establish the patient's preference for each person's role in decision-making; gather information about the patient's concerns and expectations; share medical information and evidence; recognize that a decision can and must be made in the situation; evaluate the presented information with the patient; negotiate decisions and resolve conflict; frequently check understanding of facts and perspectives; agree on a decision and an action plan; authorize final choices; and implement the agreed upon choice. Materials are available that guide providers toward effective communication (Communication Matters, 2008). Clearly, in addition to understanding the symptom trajectories of each disease and knowing the options for communication supports and intervention, it is critical that providers support effective, value-based patient-provider communication that will affect outcomes and quality of life for patients with neurodegenerative diseases that cause speech, language, and cognitive impairments.

Acknowledgments

Conflict of interest

References

Akcakaya, M., Peters, B., Moghadamfalahi, M., Mooney, A., Orhan, U., Oken, B.,... Fried-Oken, M. (2014). Noninvasive brain computer interfaces for augmentative and alternative communication. *IEEE Reviews in Biomedical Engineering*, *7*, 31-49.

American Speech-Language-Hearing Association. (No date). Augmentative and alternative communication (AAC). Retrieved from http://www.asha.org/public/speech/disorders/AAC/.

American Speech-Language-Hearing Association. (2005). Roles and responsibilities of speech-language pathologists withrespect to augmentative and alternative communication: Position-statement. Retrieved from http://www.asha.org/policy/PS2005-00113.htm#sec1.1.

Assistive Technology Law Center. (2012). AAC funding help. Retrieved from http://aacfundinghelp.com/.

Baddeley, A. (1992). Implicit memory and errorless learning: A link between cognitive theory and neuropsychological rehabilitation. In L. Squire, & N. Butters (Eds.), *Neuropsychology of Memory*. New York, NY: Guilford Press.

Ball, L. J., Anderson, E., Bilyeu, D. V., Pattee, G. L., Beukelman, D. R., & Robertson, J. (2007). Duration of AAC technology use by persons with ALS. *Journal of Medical Speech Language Pathology*, *15*(4), 371-381.

Ball, L. J., Beukelman, D. R., & Pattee, G. L. (2004). Acceptance of augmentative and alternative communication technology by persons with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, *20*(2), 113-122.

Ball, L. J., Willis, A., Beukelman, D. R., & Pattee, G. L. (2001). A protocol for identification of early bulbar signs in amyotrophic lateral sclerosis. *Journal of the Neurological Sciences*, *191*(1), 43-53.

Ball, L. J., & Lasker, J. (2013). Teaching partners to support communication for adults with acquired communication impairment. *SIG 12 Perspectives on Augmentative and Alternative Communication*, *22*(1), 4-15.

Ball, L. J., Beukelman, D. R., & Bardach, L. (2007). Amyotrophic lateral sclerosis. In D. R. Beukelman, K. L. Garrett & K. M. Yorkston (Eds.), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 287-316). Baltimore, MD: Paul H. Brookes Publishing Co.

Ball, L. J., Fager, S., & Fried-Oken, M. (2012). Augmentative and alternative communication for people with progressive neuromuscular disease. *Physical Medicine & Rehabilitation Clinics of North America*, *23*(3), 689-699.

Bauby, J. (1998). *The diving bell and the butterfly*. New York, NY: Vintage.

Bauer, G., Gerstenbrand, F., & Rumpl, E. (1979). Varieties of the locked-in syndrome. *Journal of Neurology*, *221*(2), 77-91.

Bayles, K. A., Kaszniak, A. W., & Tomoeda, C. K. (1987). *Communication and cognition in normal aging and dementia.* Boston, MA: College-Hill Press/Little, Brown & Co.

Bayles, K. A., Tomoeda, C. K., Cruz, R. F., & Mahendra, N. (2000). Communication abilities of individuals with late-stage Alzheimer disease. *Alzheimer Disease & Associated Disorders*, *14*(3), 176-181.

Beaudoin, N., & De Serres, L. (2008). Locked-in syndrome. In J. H. Stone, & M. Blouin (Eds.), *International encyclopedia of rehabilitation*. Buffalo, NY: Center for International Rehabilitation Research Information and Exchange (CIRRIE).

Beeson, P. M., King, R. M., Bonakdarpour, B., Henry, M. L., Cho, H., & Rapcsak, S. Z. (2011). Positive effects of language treatment for the logopenic variant of primary progressive aphasia. *Journal of Molecular Neuroscience*, *45*(3), 724-736.

Beukelman, D. R., Ball, L. J., & Pattee, G. L. (2004). Intervention decision-making for persons with amyotrophic lateral sclerosis. *The ASHA Leader*, 2004.

Beukelman, D. R., Garrett, K. L., & Yorkston, K. M. (2007). *Augmentative communication strategies for adults with acute or chronic medical conditions*. Baltimore, MD: Brookes Publishing Co.

Beukelman, D., Fager, S., & Nordness, A. (2011). Communication support for people with ALS. *Neurology Research International*, *2011*, 714693.

Beukelman, D., & Mirenda, P. (2013). *Augmentative and alternative communication: Supporting children and adults with complex communication needs* (4th ed.). Baltimore, MD: Brookes Publishing.

Beukelman, D. R., Fager, S., Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative & Alternative Communication*, *23*(3), 230-242.

Binger, C., Ball, L., Dietz, A., Kent-Walsh, J., Lasker, J., Lund, S.,... Quach, W. (2012). Personnel roles in the AAC assessment process. *Augmentative and Alternative Communication*, *28*(4), 278-288.

Blackstone, S., & Hunt-Berg, M. (2003). *Social networks: A communication inventory for individuals with complex communication needs and their communication partners*. Verona, WI: Attainment Company.

Blankertz, B., Dornhege, G., Krauledat, M., Schröder, M., Williamson, J., Murray-Smith, R., & Müller, K.-R. (2006). The Berlin Brain-Computer Interface presents the novel mental typewriter Hex-o-Spell. *Proceedings of the 3rd International Brain-Computer Interface Workshop and Training Course*, Graz, Austria. 108-109.

Bourgeois, M. S. (1990). Enhancing conversation skills in Alzheimer's disease using a prosthetic memory AI. *Journal of Applied Behavior Analysis*, *23*, 29-42.

Bourgeois, M. S. (1991). Communication treatment for adults with dementia. *Journal of Speech, Language, and Hearing Research*, *34*(4), 831-844.

Bourgeois, M. S. (1992). Evaluating memory wallets in conversations with persons with dementia. *Journal of Speech, Language, and Hearing Research*, *35*(6), 1344-1357.

Bourgeois, M. S., & Hickey, E. M. (2007). Dementia. In D. R. Beukelman, K. L. Garrett & K. Yorkston M. (Eds.), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 243-285). Baltimore, Maryland: Paul H. Brookes Publishing Co.

Bourgeois, M. S., Camp, C., Rose, M., White, B., Malone, M., Carr, J., & Rovine, M. (2003). A comparison of training strategies to enhance use of external aids by persons with dementia. *Journal of Communication Disorders*, *36*(5), 361-378.

Bourgeois, M. S., & Hickey, E. (2009). *Dementia: From diagnosis to management - A functional approach*. New York, NY: Taylor & Francis.

Bourgeois, M., Fried-Oken, M., & Rowland, C. (2010). AAC strategies and tools for persons with dementia. *The ASHA Leader*, 8-11.

Bourgeois, M. S., Burgio, L. D., Schulz, R., Beach, S., & Palmer, B. (1997). Modifying repetitive verbalizations of community-dwelling patients with AD. *The Gerontologist*, *37*(1), 30-39.

Brush, J. A., & Camp, C. J. (1998). Using spaced retrieval as an intervention during speech-language therapy. *Clinical Gerontologist*, *19*(1), 51-64.

Bunnell, H. T., Lilley, J., Pennington, C., Moyers, B., & Polikoff, J. (2010). The ModelTalker system. *Proceedings of the Blizzard Challenge Workshop*, Nara, Japan.

Carthery-Goulart, M. T., da Silveira, Amanda da Costa, Machado, T. H., Mansur, L. L., Parente, Maria Alice de Mattos Pimenta, Senaha, M. L. H.,... Nitrini, R. (2013). Nonpharmacological interventions for cognitive impairments following primary progressive aphasia. *Dementia and Neuropsychology*, *7*(1), 122-131.

Carthery-Goulart, M. T., Knibb, J. A., Patterson, K., & Hodges, J. R. (2012). Semantic dementia versus nonfluent progressive aphasia: Neuropsychological characterization and differentiation. *Alzheimer Disease & Associated Disorders*, *26*(1), 36-43.

Casanova, E., Lazzari, R. E., Lotta, S., & Mazzucchi, A. (2003). Locked-in syndrome: Improvement in the prognosis after an early intensive multidisciplinary rehabilitation. *Archives of Physical Medicine and Rehabilitation*, *84*(6), 862-867.

Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons-Mackie, N. (2001). Life participation approach to aphasia: A statement of values for the future. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (4th ed., pp. 279-289). Philadelphia, PA: Lippincott Williams & Wilkins.

Communication Matters. (2008). *Communicating with patients who have speech/language difficulties: Guidance for medical & nursing staff*. Available from: http://www.patientprovider communication.org/pdf/2.pdf.

Costello, J. (2014). Preserving legacy: Being proactive with ALS, message banking-& low-tech strategies. Presented at the 2014 American Speech-Language-Hearing Association Convention, Orlando, FL.

Costello, J., & Dimery, K. (2014). Preserving legacy: A guide to message banking in a patient's voice. Presented at the 16th Biennial Conference of the International Society for Augmentative and Alternative Communication, Lisbon, Portugal.

Cress, C., & King, J. (1999). AAC strategies for people with primary progressive aphasia without dementia: Two case studies. *Augmentative and Alternative Communication*, *15*(4), 248.

Croot, K., Nickels, L., Laurence, F., & Manning, M. (2009). Impairment-and activity/participation-directed interventions in progressive language impairment: Clinical and theoretical issues. *Aphasiology*, *23*(2), 125-160.

Darley, F. L., Aronson, A. E., & Brown, J. R. (1969). Clusters of deviant speech dimensions in the dysarthrias. *Journal of Speech, Language, and Hearing Research*, *12*(3), 462-496.

Dijkstra, K., Bourgeois, M. S., Allen, R. S., & Burgio, L. D. (2004). Conversational coherence: Discourse analysis of older adults with and without dementia. *Journal of Neurolinguistics*, *17*(4), 263-283.

Doble, J. E., Haig, A. J., Anderson, C., & Katz, R. (2003). Impairment, activity, participation, life satisfaction, and survival in persons with locked-in syndrome for over a decade: Follow-up on a previously reported cohort. *The Journal of Head Trauma Rehabilitation*, *18*(5), 435-444.

Doyle, M., & Phillips, B. (2001). Trends in augmentative and alternative communication use by individuals with amyotrophic lateral sclerosis. *Augmentative and Alternative Communication*, *17*(3), 167-178.

Dworkin, J. P., & Hartman, D. E. (1979). Progressive speech deterioration and dysphagia in amyotrophic lateral sclerosis: Case report. *Archives of Physical Medicine and Rehabilitation*, *60*(9), 423-425.

Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, *25*(3), 345-358.

Fabiani, M., Gratton, G., Karis, D., & Donchin, E. (1987). Definition, identification, and reliability of measurement of the P300 component of the event-related brain potential. *Advances in Psychophysiology*, *2*, 1-78.

Fager, S., Beukelman, D. R., Fried-Oken, M., Jakobs, T., & Baker, J. (2012). Access interface strategies. *Assistive Technology*, *24*(1), 25-33.

Farwell, L. A., & Donchin, E. (1988). Talking off the top of your head: Toward a mental prosthesis utilizing event-related brain potentials. *Electroencephalography & Clinical Neurophysiology*, *70*(6), 510-523.

Fishman, I. (1987). *Electronic communication aids: Selection and use*. San Diego, CA: College Hill.

Fox, L. E., & Sohlberg, M. M. (2000). Meaningful communication roles. In D. Beukelman, K. Yorkston & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 3-24). Baltimore, MD: Brookes Publisher Co.

Fried-Oken, M. (2008). Augmentative and alternative communication treatment for persons with primary progessive aphasia. *Perspectives on Augmentative and Alternative Communication*, *17*, 99-104.

Fried-Oken, M., Beukelman, D., & Hux, K. (2012). Current and future AAC research considerations for adults with acquired cognitive and communication impairments. *Assistive Technology*, *24*, 56-66.

Fried-Oken, M., Rau, M. T., & Oken, B. S. (2000). AAC and dementia. In D. R. Beukelman, K. M. Yorkston & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 375-406) Paul H. Brookes Publishing Co.

Fried-Oken, M., Rowland, C., & Gibbons, C. (2010). Providing augmentative and alternative communication treatment to persons with progressive nonfluent aphasia. *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, *20*, 21-25.

Fried-Oken, M., Howard, J., & Stewart, S. R. (1991). Feedback on AAC intervention from adults who are temporarily unable to speak. *Augment Altern Commun*, *7*(1), 43-50.

Fried-Oken, M., Rowland, C., Daniels, D., Dixon, M., Fuller, B., Mills, C.,... Oken, B. (2012). AAC to support conversation in persons with moderate Alzheimer's disease. *Augmentative and Alternative Communication*, *28*(4), 219-231.

Fried-Oken, M., Fox, L., Rau, M. T., Tullman, J., Baker, G., Hindal, M.,... Lou, J. -. (2006). Purposes of AAC device use for persons with ALS as reported by caregivers. *AAC: Augmentative and Alternative Communication*, *22*(3), 209-221.

Goldstein, L. H., & Abrahams, S. (2013). Changes in cognition and behaviour in amyotrophic lateral sclerosis: Nature of impairment and implications for assessment. *The Lancet Neurology*, *12*(4), 368-380.

Goosens', C., & Crain, S. (1987). Overview of nonelectronic eye-gaze communication techniques. *Augmentative and Alternative Communication*, *3*(2), 77-89.

Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F.,... Grossman, M. (2011). Classification of primary progressive aphasia and its variants. *Neurology*, *76*(11), 1006-1014.

Hanson, E. K., Yorkston, K. M., & Beukelman, D. R. (2004). Speech supplementation techniques for dysarthria: A systematic review. *Journal of Medical Speech-Language Pathology*, *12*(2).

Hanson, E. K., Beukelman, D. R., Heidemann, J. K., & Shutts-Johnson, E. (2010). The impact of alphabet supplementation and word prediction on sentence intelligibility of electronically distorted speech. *Speech Communication*, *52*(2), 99-105.

Hanson, E. K., Beukelman, D. R., & Yorkston, K. M. (2013). Communication support through multimodal supplementation: A scoping review. *Augmentative and Alternative Communication*, *29*(4), 310-321.

Hanson, E. K., Yorkston, K. M., & Britton, D. (2011). Dysarthria in amyotrophic lateral sclerosis: A systematic review of characteristics, speech treatment, and augmentative and alternative communication options. *Journal of Medical Speech-Language Pathology*, *19*(3), 12-30.

Haskard Zolnierek, K. B., & DiMatteo, M. R. (2009). Physician communication and patient adherence to treatment: A meta-analysis. *Medical Care*, *47*(8), 826-834.

Hayashi, H., Kato, S., & Kawada, A. (1991). Amyotrophic lateral sclerosis patients living beyond respiratory failure. *Journal of the Neurological Sciences*, *105*(1), 73-78.

Hayashi, H., & Oppenheimer, E. A. (2003). ALS patients on TPPV: Totally locked-in state, neurologic findings and ethical implications. *Neurology*, *61*(1), 135-137.

Henry, M. L., Beeson, P. M., & Rapcsak, S. Z. (2008). Treatment for anomia in semantic dementia. *Seminars in Speech and Language*, *29*(1), 60-70.

Ho, K. M., Weiss, S. J., Garrett, K. L., & Lloyd, L. L. (2005). The effect of remnant and pictographic books on the communicative interaction of individuals with global aphasia. *Augmentative and Alternative Communication*, *21*(3), 218-232.

Hoffman, P., Meteyard, L., & Patterson, K. (2014). Broadly speaking: Vocabulary in semantic dementia shifts towards general, semantically diverse words. *Cortex*, *55*(30), 42.

Hopper, T., Bourgeois, M., Pimentel, J., Qualls, C. D., Hickey, E., Frymark, T., & Schooling, T. (2013). An evidence-based systematic review on cognitive interventions for individuals with dementia. *American Journal of Speech-Language Pathology*, *22*(1), 126-145.

Houston, S. (2000). Reflections on a kayak expedition in scotland. In M. Fried-Oken, & H. Bersani (Eds.), *Speaking up and spelling it out: Personal essays on augmentative and alternative communication*. Baltimore, MD: Paul Brookes Publishers.

Hustad, K. C., Jones, T., & Dailey, S. (2003). Implementing speech supplementation strategies: Effects on intelligibility and speech rate of individuals with chronic severe dysarthria. *Journal of Speech, Language, and Hearing Research*, *46*(2), 462-474.

Jokel, R., Graham, N. L., Rochon, E., & Leonard, C. (2014). Word retrieval therapies in primary progressive aphasia. *Aphasiology*, *28*(8-9), 1038-1068.

Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, *12*(9), 816-830.

Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., Sharp, S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, *22*(3), 258-280.

Kagan, A., Black, S. E., Duchan, J. F., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using "supported conversation for adults with aphasia" (SCA): A controlled trial. *Journal of Speech, Language and Hearing Research*, *44*(3), 624-638.

Kempler, D. (1995). Language changes in dementia of the Alzheimer's type. In R. Lubinski (Ed.), *Dementia and communication* (pp. 98-114) Philadelphia: Decker.

Kent-Walsh, J., & Mcnaughton, D. (2005). Communication partner instruction in AAC: Present practices and future directions. *Augmentative and Alternative Communication*, *21*(3), 195-204.

Kertesz, A. (1994). Language deterioration in dementia. In V. O. B. Emery, & T. E. Oxman (Eds.), *Dementia: Presentations, Differential Diagnosis and Nosology* (pp. 123-138). Baltimore, MD: Johns Hopkins University Press.

Khayum, B., Wieneke, C., Rogalski, E., Robinson, J., & O'Hara, M. (2012). Thinking outside the stroke: Treating primary progressive aphasia (PPA). *SIG 15 Perspectives on Gerontology*, *17*(2), 37-49.

King, J. M., Simmons-Mackie, N., & Beukelman, D. R. (2013). Supporting communication: Improving the lives of people with aphasia. In N. Simmons-Mackie, J. M. King & D. R. Beukelman (Eds.), *Supporting communication for adults with acute and chronic aphasia*. Baltimore, MD: Brookes Publishing Co.

King, J. M., Alarcon, N., & Rogers, M. A. (2007). Primary progressive aphasia. In D. R. Beukelman, K. L. Garrett & K. Yorkston M. (Eds.), *Augmentative communication strategies for adults with acute or chronic medical conditions* (pp. 207-241). Baltimore, Maryland: Paul H. Brookes Publishing Co.

Kortte, K. B., & Rogalski, E. J. (2013). Behavioural interventions for enhancing life participation in behavioural variant frontotemporal dementia and primary progressive aphasia. *International Review of Psychiatry*, *25*(2), 237-245.

Krusienski, D. J., Sellers, E. W., McFarland, D. J., Vaughan, T. M., & Wolpaw, J. R. (2008). Toward enhanced P300 speller performance. *Journal of Neuroscience Methods*, *167*(1), 15-21.

Kühnlein, P., Gdynia, H., Sperfeld, A., Lindner-Pfleghar, B., Ludolph, A. C., Prosiegel, M., & Riecker, A. (2008). Diagnosis and treatment of bulbar symptoms in amyotrophic lateral sclerosis. *Nature Clinical Practice Neurology*, *4*(7), 366-374.

Kuwahara, N., Yasuda, K., Tetsutani, N., & Morimoto, K. (2010). Remote assistance for people with dementia at home using reminiscence systems and a schedule prompter. *International Journal of Computers in Healthcare*, *1*(2), 126-143.

Lasker, J., Hux, K., Garrett, K., Moncrief, E., & Eischeid, T. (1997). Variations on the written choice communication strategy for individuals with severe aphasia. *Augmentative and Alternative Communication*, *13*(2), 108-116.

Leyton, C. E., & Hodges, J. R. (2014). Differential diagnosis of primary progressive aphasia variants using the international criteria. *Aphasiology*, *28*(8-9), 909-921.

Lomen-Hoerth, C., Murphy, J., Langmore, S., Kramer, J. H., Olney, R. K., & Miller, B. (2003). Are amyotrophic lateral sclerosis patients cognitively normal? *Neurology*, *60*(7), 1094-1097.

Lyon, J., Cariski, D., Keisler, L., Rosenbek, J., Levine, R., Kumpula, J.,... Blanc, M. (1997). Communication partners: Enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology*, *11*(7), 693-708.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E. M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA work group under the auspices of Department of Health and Human Services task force on Alzheimer's disease. *Neurology*, *34*(7), 939-944.

McKitrick, L. A., Camp, C. J., & Black, F. W. (1992). Prospective memory intervention in Alzheimer's disease. *Journal of Gerontology*, *47*(5), 337-343.

McNaughton, D., Light, J., & Groszyk, L. (2001). "Don't give up": Employment experiences of individuals with amyotrophic lateral sclerosis who use augmentative and alternative communication. *Augmentative and Alternative Communication*, *17*(3), 179-195.

Mesulam, M. M. (1982). Slowly progressive aphasia without generalized dementia. *Annals of Neurology*, *11*(6), 592-598.

Mesulam, M., Wieneke, C., Rogalski, E., Cobia, D., Thompson, C., & Weintraub, S. (2009). Quantitative template for subtyping primary progressive aphasia. *Archives of Neurology*, *66*(12), 1545-1551.

Mesulam, M. M. (2001). Primary progressive aphasia. *Annals of Neurology*, *49*(4), 425-432.

Mesulam, M. M. (2013). Primary progressive aphasia and the language network: The 2013 H. Houston Merritt lecture. *Neurology*, *81*(5), 456-462.

Mesulam, M. M., & Weintraub, S. (1992). Spectrum of primary progressive aphasia. *Baillière's Clinical Neurology*, *1*(3), 583-609.

Murguialday, A. R., Hill, J., Bensch, M., Martens, S., Halder, S., Nijboer, F.,... Gharabaghi, A. (2011). Transition from the locked in to the completely locked-in state: A physiological analysis. *Clinical Neurophysiology*, *122*(5), 925-933.

Murphy, J., Gray, C. M., van Achterberg, T., Wyke, S., & Cox, S. (2010). The effectiveness of the Talking Mats framework in helping people with dementia to express their views on well-being. *Dementia*, *9*(4), 454-472.

Murphy, J., & Oliver, T. (2013). The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health and Social Care in the Community*, *21*(2), 171-180.

National Joint Committee for the Communication Needs of Persons with Severe Disabilities. (1992). Guidelines for meeting the communication needs of persons with severe disabilities. *ASHA*, *34*(Suppl. 7), 2-3.

Neary, D., Snowden, J. S., & Mann, D. M. A. (2000). Cognitive change in motor neurone disease/amyotrophic lateral sclerosis (MND/ALS). *Journal of the Neurological Sciences*, *180*(1), 15-20.

Ogar, J. M., Dronkers, N. F., Brambati, S. M., Miller, B. L., & Gorno-Tempini, M. L. (2007). Progressive nonfluent aphasia and its characteristic motor speech deficits. *Alzheimer Disease and Associated Disorders*, *21*(4), S23-30.

Oken, B. S., Orhan, U., Roark, B., Erdogmus, D., Fowler, A., Mooney, A.,... Fried-Oken, M. B. (2014). Brain-computer interface with language model-electroencephalography fusion for locked-in syndrome. *Neurorehabilitation and Neural Repair*, *28*(4), 387-394.

Orhan, U., Hild II, K. E., Erdogmus, D., Roark, B., Oken, B., & Fried-Oken, M. (2012). RSVP keyboard: An EEG based typing interface. *2012 IEEE International Conference on Acoustics, Speech, and Signal Processing, ICASSP 2012,* Kyoto. 645-648.

Patient Provider Communication. (2014). Patient provider communication website. Retrieved from http://www.patient providercommunication.org/

Pattee, C., Von Berg, S., & Ghezzi, P. (2006). Effects of alternative communication on the communicative effectiveness of an individual with a progressive language disorder. *International Journal of Rehabilitation Research*, *29*(2), 151-153.

RERC on Communication Enhancement. (2004a). *Patient's clinical pathway for communication changes with ALS, version 5.3.* Available from: http://aac-rerc.psu.edu/index.php/files/list/type/1

RERC on Communication Enhancement. (2004b). *Speech pathologist's clinical pathway for communication changes with ALS, version 5.3.* Available from: http://aac-rerc.psu.edu/index.php/files/list/type/1

Ringel, S. P., Murphy, J. R., Alderson, M. K., Bryan, W., England, J. D., Miller, R. G.,... Yu, P. (1993). The natural history of amyotrophic lateral sclerosis. *Neurology*, *43*(7), 1316-1322.

Rising, K. (2014). Treatment for lexical retrieval in primary progressive aphasia. *SIG 2 Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, *24*(4), 137-144.

Rogers, M., King, J. M., & Alarcon, N. (2000). Proactive management of primary progressive aphasia. In D. Beukelman, K. Yorkston & J. Reichle (Eds.), *Augmentative and alternative communication for adults with acquired neurologic disorders* (pp. 305-337). Baltimore, MD: Brookes Publisher Co.

Rogers, M. A., & Alarcon, N. B. (1998). Dissolution of spoken language in primary progressive aphasia. *Aphasiology*, *12*(7-8), 635-650.

Roman, A. (2014). Amy & PALS: ALS speech and communication solutions plus tips from various ALS experts. Retrieved from http://amyandpals.com/

Roman, A., & Woolley Levine, S. (2006). Cognitive and behavioral impairments in people with ALS and their implications for communication and AAC use. *SIG 12 Perspectives on Augmentative and Alternative Communication*, *15*(4), 9-14.

Rowland, L. P. (Ed.). (2005). *Merritt's neurology* (11th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Ryan, D. B., Frye, G. E., Townsend, G., Berry, D. R., Mesa-G, S., Gates, N. A., & Sellers, E. W. (2011). Predictive spelling with a P300-based brain–computer interface: Increasing the rate of communication. *International Journal of Human-Computer Interaction*, *27*(1), 69-84.

Santiago, R., & Costello, J. M. (2013). AAC assessment and intervention in pediatric ICU/acute care: From referral through continuum of care. *Perspectives on Augmentative and Alternative Communication*, *22*(2), 102-111.

Schalk, G., McFarland, D. J., Hinterberger, T., Birbaumer, N., & Wolpaw, J. R. (2004). BCI2000: A general-purpose brain-computer interface (BCI) system. *IEEE Transactions on Biomedical Engineering*, *51*(6), 1034-1043.

Scherer, M., Jutai, J., Fuhrer, M., Demers, L., & Deruyter, F. (2007). A framework for modelling the selection of assistive technology devices (ATDs). *Disability & Rehabilitation: Assistive Technology*, *2*(1), 1-8.

Schjolberg, A., & Sunnerhagen, K. S. (2012). Unlocking the locked in; a need for team approach in rehabilitation of survivors with locked-in syndrome. *Acta Neurologica Scandinavica*, *125*(3), 192-198.

Sellers, E. W., Vaughan, T. M., & Wolpaw, J. R. (2010). A brain-computer interface for long-term independent home use. *Amyotrophic Lateral Sclerosis*, *11*(5), 449-455.

Shane, H. C., Blackstone, S., Vanderheiden, G., Williams, M., & DeRuyter, F. (2012). Using AAC technology to access the world. *Assistive Technology*, *24*(1), 3-13.

Simmons-Mackie, N. (2013). Frameworks for managing communication support for people with aphasia. In N. Simmons-Mackie, J. M. King & D. R. Beukelman (Eds.), *Supporting communication for adults with acute and chronic aphasia*. Baltimore, MD: Brookes Publishing Co.

Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, L. R. (2010). Communication partner training in aphasia: A systematic review. *Archives of Physical Medicine and Rehabilitation*, *91*(12), 1814-1837.

Sitver, M., & Kraat, A. (1982). Augmentative communication for the person with amyotrophic lateral sclerosis (ALS). *ASHA, 24*, 783.

Small, J. A., Gutman, G., Makela, S., & Hillhouse, B. (2003). Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living. *Journal of Speech, Language, and Hearing Research*, *46*(2), 353-367.

Smith, M. M., & Connolly, I. (2008). Roles of aided communication: Perspectives of adults who use AAC. *Disability & Rehabilitation: Assistive Technology*, *3*(5), 260-273.

Soderholm, S., Meinander, M., & Alaranta, H. (2001). Augmentative and alternative communication methods in locked-in syndrome. *Journal of Rehabilitation Medicine*, *33*(5), 235-239.

Taylor, L. J., Brown, R. G., Tsermentseli, S., Al-Chalabi, A., Shaw, C. E., Ellis, C. M.,... Goldstein, L. H. (2013). Is language impairment more common than executive dysfunction in amyotrophic lateral sclerosis? *Journal of Neurology, Neurosurgery, and Psychiatry*, *84*(5), 494-498.

The Joint Commission. (2010). *Advancing effective communication, cultural competence, and patient- and family-centered care:*

A roadmap for hospitals. Oakbrook Terrace, IL: The Joint Commission.

Thiessen, A., & Beukelman, D. (2013). Training communication partners of adults who rely on AAC: Co-construction of meaning. *Perspectives on Augmentative and Alternative Communication*, *22*(1), 16-20.

Thompson, C. K., & Mack, J. E. (2014). Grammatical impairments in PPA. *Aphasiology*, *28*(8-9), 1018-1037.

Treder, M. S., Schmidt, N., & Blankertz, B. (2011). Gaze-independent visual brain-computer interfaces. *International Journal of Bioelectromagnetism*, *13*(1), 11-12.

Vanderheiden, G. C., & Yoder, D. E. (1986). Overview. In S. W. Blackston (Ed.), *Augmentative communication: An introduction* (pp. 1-28). Rockville, MD: American Speech-Language-Hearing Association.

Vasse, E., Vernooij-Dassen, M., Spijker, A., Rikkert, M. O., & Koopmans, R. (2010). A systematic review of communication strategies for people with dementia in residential and nursing homes. *International Psychogeriatrics*, *22*(02), 189-200.

Wallace, S. E., Dietz, A., Hux, K., & Weissling, K. (2012). Augmented input: The effect of visuographic supports on the auditory comprehension of people with chronic aphasia. *Aphasiology*, *26*(2), 162-176.

Watts, C. R., & Vanryckeghem, M. (2001). Laryngeal dysfunction in amyotrophic lateral sclerosis: A review and case report. *BMC Ear, Nose, and Throat Disorders*, *1*(1), 1.

Weiss, B. D. (2007). *Health literacy and patient safety: Help patients understand. Manual for clinicians* (2nd ed.). Chicago, IL: American Medical Association Foundation and American Medical Association.

Williams, M. V., Davis, T., Parker, R. M., & Weiss, B. D. (2002). The role of health literacy in patient-physician communication. *Family Medicine*, *34*(5), 383-389.

Wilson, B. A., Baddeley, A., Evans, J., & Shiel, A. (1994). Errorless learning in the rehabilitation of memory impaired people. *Neuropsychological Rehabilitation*, *4*(3), 307-326.

Winden, S., Carmack, C. S., Corda, D. E., McFarland, D. J., Zeitlin, D., Tenteramano, L.,... Wolpaw, J. R. (2012). BCI-360: Full-service support for independent home-based BCI use and for translational studies. *Neuroscience 2012 Abstracts*, New Orleans, LA.

Wolpaw, J. R., Birbaumer, N., McFarland, D. J., Pfurtscheller, G., & Vaughan, T. M. (2002). Brain-computer interfaces for communication and control. *Clinical Neurophysiology*, *113*(6), 767-791.

Woolley, S. C., York, M. K., Moore, D. H., Strutt, A. M., Murphy, J., Schulz, P. E., & Katz, J. S. (2010). Detecting frontotemporal dysfunction in ALS: Utility of the ALS Cognitive Behavioral Screen (ALS-CBS™). *Amyotrophic Lateral Sclerosis*, *11*(3), 303-311.

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: World Health Organization.

Worrall, L. E., & Frattali, C. M. (2000). *Neurogenic communication disorders: A functional approach*. New York, NY: Thieme.

Wu, Y. C., & Voda, J. A. (1985). User-friendly communication board for nonverbal, severely physically disabled individuals. *Archives of Physical Medicine and Rehabilitation*, *66*(12), 827-828.

Yarrington, D., Pennington, C., Bunnell, H. T., Gray, J., Lilley, J., Nagao, K., & Polikoff, J. (2008). ModelTalker Voice Recorder (MTVR)-A system for capturing individual voices for synthetic speech. *ISAAC 13th Biennial Conference*, Montreal, Canada.

Yarrington, D., Pennington, C., Gray, J., & Bunnell, H. T. (2005). A system for creating personalized synthetic voices. *Proceedings of the 7th International ACM SIGACCESS Conference on Computers and Accessibility*, Baltimore, MD. 196-197.

Yasuda, K., Kuwabara, K., Kuwahara, N., Abe, S., & Tetsutani, N. (2009). Effectiveness of personalised reminiscence photo videos for individuals with dementia. *Neuropsychological Rehabilitation*, *19*(4), 603-619.

Yorkston, K., Baylor, C., Burns, M., Morris, M., & McNalley, T. (2015). Medical education: Preparing professionals to enhance communication access in healthcare setting. In S. W. Blackstone, D. Beukelman & K. Yorkston (Eds.), *Patient provider communication: Roles of speech-language pathologists and other health care professionals* (pp. 37-72). San Diego, CA: Plural Publishing.

Yorkston, K. M., Beukelman, D. R., Strand, E. A., & Bell, K. R. (1999). *Management of motor speech disorders in children and adults*. Austin, TX: PRO-ED.

Zangari, C., & Wasson, C. A. (1997). Service delivery and funding. In L. L. Lloyd, D. R. Fuller & H. H. Arvidson (Eds.), *Augmentative and alternative communication: A handbook of principles and practices* (pp. 389-405). Boston, MA: Allyn & Bacon.